

Pharmacoeconomics Journal. Article Title: Health Economists on Involving Patients in Modelling: Potential Benefits, Harms, and Variables of Interest. Online Resource 3: Interview Guide. Authors: Stephanie Harvard and Gregory R. Werker. Corresponding Author: Stephanie Harvard, University of British Columbia Faculty of Pharmaceutical Sciences, harvards@mail.ubc.ca.

Interview Guide:

Social, Ethical, and Other Value Judgments in Health Economics and Simulation Modelling

**Material in italics will not be read aloud during the interview but is noted in case further clarification and/or a reference is desired by the participant*

1. Introduction- describe project and define terms

- The purpose of this conversation is to know your views on **values** and **value judgments** in health economics and simulation modelling studies.
- The reason for doing this is **people still disagree about the role of values in science**. This applies across the disciplines and there is a **lack of conversation in health economics and simulation modelling** in particular. So this is why we want to talk to people in the field about this topic, and why we appreciate your participation.
- There is more than one definition of 'values' so let me clarify how I'll be using this term. In this conversation, I will use 'values' in the very broadest sense, to refer to anything "desirable or worthy of pursuit"* (*Kevin Elliott's 2017 term), anything 'good'.
- In the modelling context, 'values' in this broad sense includes things like **predictive power** or **accuracy** or **robustness**, because these are things that are considered to be good attributes of a model. Sometimes people refer to these values as '**scientific criteria**'.
- In the modelling context, values also include things like **relevance to decision-makers**, **comprehensiveness**, or **usability**. Sometimes people refer to these values as '**social and ethical**' or just '**social**' values*. *e.g., Winsberg (2012), "Social values, I take it, are the estimations of any agent or group of agents of what is important and valuable—in the typical social and ethical senses—and of what is to be avoided, and to what degree."
- That said, many people **don't draw sharp lines** between scientific criteria and social values. Today, I'll just refer to 'values' except where it is useful to make the distinction.
- About the term '**value judgments**': People use this term differently and it's hard to define it perfectly, so I'll tell you the rough definition that we're using in this project. We're interested in decisions where:
 - 1) There is **flexibility from a scientific perspective**, in that scientists agree there is more than one legitimate method or way of doing things; AND
 - 2) There could be **social or ethical consequences** following the decision, whether these consequences are immediate or down the line.
- But if that definition raises difficulties at any point, we can make that part of the discussion.

2. Please tell me a bit about yourself

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- Your work in modelling
- If the issue of values in science is something you've thought about a little, a lot, not at all, in between, etc.

3. Thinking about the modelling that you do, what are the major stages in the process? In other words, how do you get from the beginning of an idea to a completely finished model? I'm talking big picture here, and just for the purpose of having these in mind as we move on.

3b. Thinking about major stages in the modelling process, can you describe which stages, if any, you feel require making value judgments?

3c. Again thinking about major stages in the modelling process, can you describe which stages, if any, you feel do not require making value judgments?

4. Thinking now in more detail within the stages in modelling, can you tell me some of the specific decisions that you're required to make in each stage?

4b. Can you help me understand how you think about these decisions, whether you think of any of them as being value judgments?

[THE FOLLOWING MATERIAL WILL BE CIRCULATED TO PARTICIPANTS IN ADVANCE]

5. There are a few arguments in the literature about how social values become part of science, which continue to be debated. These arguments are described in the interview package we circulated. I would like to know your views on these, so I will just go through them if that's ok by you.

a) Argument from value-laden background assumptions*: Scientists never start from scratch, but must incorporate at least some background assumptions into their work. For example, it may be assumed that a diagnosis of disease has only negative consequences for a patient. Certain assumptions align with and advance certain values and not others.

**Kristina Rolin's term (Rolin 2016)*

Would you tell me your general reaction to this idea?

Would there be an example from your own work, of a "background assumption" in modelling?

Would there be an example from your own work, where a "background assumption" might have introduced social values into the model?

b1) Boundary Challenge*- version 1 (one value, two interpretations): It is not always possible to distinguish between scientific criteria and social values, and some scientific criteria can introduce social values. For example, we might describe gender using 2 categories, because this

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can simplify data analysis. But this also perpetuates the binary conception of gender, which aligns with certain social values and conflicts with others.**

** Heather Douglas' term (Douglas 2016)*

***This idea appears in Rooney 1992*

Would you tell me your general reaction to this idea?

Would there be an example from your own work, where scientific criteria might have introduced social values?

b2) Boundary Challenge- version 2 (two values, tradeoff situation):** It is seldom possible to maximize all scientific criteria in a single model, and social values are used to make tradeoffs* between scientific criteria. For example, there may be necessary trade-offs between accuracy and speed of generating results, or between parameter precision and generalizability, which are informed by the goal of the research and therefore social values.

***This idea appears in Elliott and McKaughn 2014. I'm including it under the 'Boundary Challenge' as in a response to Elliott and McKaughn 2014, Steel (2016) disputes that speed is a non-epistemic value, bringing us back to Boundary Challenge version 1.*

Would you tell me your general reaction to this idea?

Would there be an example from your own work, where a tradeoff between two scientific values was informed by social values?

c1) Argument from inductive risk- classic version*: Scientists must decide when there is enough evidence to make a claim. This requires considering the ethical consequences of error, so requires social values. For example, if testing whether a batch of parachutes was defective, one might use a higher standard of evidence than if testing whether a batch of hairclips was defective.

**Widely attributed to Rudner 1953. Note hypothesis testing example has been modified to 'make a claim' so as not to divert into a frequentist/Bayesian debate.*

Would you tell me your general reaction to this idea?

Would there be an example from your own work, where the process for deciding when there was "enough evidence" to make a claim was informed by social values?

c2) Argument from inductive risk- extended version*: Scientists must decide when there is enough evidence to take action under uncertainty- for example, to classify ambiguous data one way or another, to use a certain model, or even populate a parameter value. This requires considering the ethical consequences of error, so requires social values.

**Douglas 2000. Various other adaptations/extensions in eds. Elliott & Richards (2017)*

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*** Steel (2015) has remarked that choosing personal probabilities used in Bayesian analyses of confirmation comes with uncertainty- so the argument from inductive risk could apply there as well.*

Would you tell me your general reaction to this idea?

Would there be an example from your own work, where the process for deciding when there was "enough evidence" to take action under uncertainty was informed by social values?

d) Cascade argument*: Value judgments in the early phases of science, such as picking the topic, picking the model structure, prioritizing model features, etc. have downstream consequences for knowledge and our conceptions of objectivity.

**A big-picture version of this argument is made by Elliott and McKaughn (2009). A more context-specific version of the argument is made by Parker and Winsberg (2018), who focus on mathematical and computer simulation models that act as "surrogates for background knowledge" in Bayesian and other studies that aim to assign probabilities to hypotheses. They assert that early choices in the modelling process, including choices of what are the model's purpose and priorities, e.g., where accuracy is most important, ultimately affect evidence evaluation/conclusions. The focus on purpose and priorities is also a theme in Elliott and McKaughn 2014.*

Would you tell me your general reaction to this idea?

Would there be an example from your own work, where early choices in model construction might have introduced social values?

8. Before we close, I would like to ask your views about having patients involved in the modelling process. Do you have any thoughts about this as a potential?

9. Do you have any other thoughts you would like to share on the topic of values or value judgments in modelling?

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